# National Assembly for Wales' Health, Wellbeing and Local Government Committee's Inquiry into Presumed Consent for Organ Donation.

# Memorandum from the British Humanist Association.

- 1. The British Humanist Association (BHA) welcomes the opportunity to submit evidence to the inquiry into organ donation and transplantation.
- 2. The BHA is the principal organisation representing the interests of the large and growing population of ethically concerned but non-religious people living in the UK. It exists to support and represent people who seek to live good and responsible lives without religious or superstitious beliefs. It is committed to human rights and democracy, and has a long history of active engagement in work for an open and inclusive society. The BHA's policies are informed by its members, who include eminent authorities in many fields, and by other specialists and experts who share humanist values and concerns.

#### Our position

- 3. Humanists generally support scientists and researchers in their quest for knowledge, and support scientific and medical advances for the improvement of our health. Most of us would not object to our body parts and organs being donated and used for good ends. We believe that better public education about organ donation and transplantation is essential, and that policy actions at both state and European levels are needed in order to increase the number of organ transplants and so save lives.
- 4. We are also very concerned that the low number and availability of organs donated across Europe is contributing to unnecessary deaths for want of transplants and to an increased trafficking in organs, and in human beings for the purpose of removal of organs, from outside of Europe and that this will create serious ethical issues and is contributing to systematic human rights violations of some of the most vulnerable people from across the world.
- 5. This response is from a humanist perspective and covers in particular issues arising from that view, the health and social welfare benefits and ethical issues of organ transplantation, the use of living donors and, especially, the 'presumed consent' approach and the arrangements for taking into account the views of relatives. We wholly oppose general policy being made on the basis of religious dogma or superstition though we recognise that provision must be made to accommodate the personal wishes of individuals based on such considerations and we support policy-making based on evidence, rational decision-making and that which seeks to maximise the well-being of individuals and so society more generally.
- 6. With any change to the approaches for organ donation for transplantation, there must be appropriate safeguards in place to protect the wishes of the deceased individual, and the health of both living donors and those needing an organ transplantation.

## **Presumed consent**

7. Humanists are concerned with the maximisation of well-being of individuals for the social good and benefit of society as a whole. Humanists believe in individual rights and freedoms - but believe that individual responsibility, social cooperation and

mutual respect are just as important. In terms of organ donation and transplantation, most humanists would consider that we have a moral responsibility to allow our organs to be used for transplantation, if that will improve the quality of life for others and contribute to the well-being of the human family.

- 8. The BHA holds that the current system where individuals must 'opt in' to have their organs removed for donation after their death has contributed to the present shortage of organs and so to many preventable deaths every year. We fully support the replacement of the opting in approach to one of 'presumed consent', whereby individuals must actively opt out should they not wish their organs to be used for donation after their death.
- 9. The presumed consent approach would better match the fact that the majority of the population support organ donation for transplantation, would be likely to vastly increase the number and availability of organs suitable for transplantation, would decrease the trafficking in organs and human beings, would increase awareness of organ donation more generally and would better assist individuals and families to make decisions about organ donation.
- 10. Under the present system, unless someone has actively opted in, it is usually left to relatives to consent to donation of the deceased's organs. There is a range of reasons why relatives may not wish the individual's organs to be donated historical, cultural, social, religious and so on but these may actually have been in direct conflict with the views of the individual. Under a system of presumed consent, supported by good public information, education and awareness of that system, if an individual has particularly strong objections to organ donation after death, then she is able make her feelings clear and opt out, while she is alive. Moreover, the presumed consent system seems better able to protect the wishes of someone who had not opted-out, even if the relatives themselves have strong views against organ transplantation, because the individual should have been given good enough information to make an informed choice when she was alive and the presumed consent should usually be taken as paramount.
- 11. This is not to say that relatives' views should never be taken into account. We would support the British Medical Association's 'soft' system of 'presumed consent', whereby organ donation (for those over the age of 16) is the default position, but where relatives would not be asked to consent to donation (as in the present system), but would be told that the individual had not opted out and would be asked if they are aware of any unregistered objection<sup>1</sup>. We believe that this would help decrease the number of objections from relatives.

### Living volunteers

12. The BHA would support a policy move to promote the altruistic donation of organs, such as kidneys, from living donors. As with any change to the organ donation after death system, this would need to be accompanied by raising public awareness through comprehensive education and information. If someone wishes to be a living volunteer donor, that must be an individual choice. She must have enough information to make a rational choice for herself about the risks of such a procedure to her well-being and life compared with the benefits to the well-being and health of the person needing that organ. We wholly endorse the present ban on a sale of organs.

<sup>&</sup>lt;sup>1</sup> British Medical Association (2007) 'Organ donation – presumed consent for organ donation', October 2007. http://tinyurl.com/2yc7u9

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